

Chapter 1

Introduction

General Objectives

Under contract RFP: HCFA-98-002/P¹ conducted under Master Contract Number 500-96-0008 between Centers for Medicare & Medicaid Services (CMS) and the University of Minnesota between 1998 and 2003, the University of Minnesota undertook a large-scale iterative study of quality of life (QOL) in nursing homes. We had two general objectives, each with several components.

Objective 1. Develop and test measures and indicators of QOL for nursing home residents;

Objective 2. Determine how physical environments in nursing homes affect QOL.

The two objectives of the study are quite distinct in their goals and tasks, but are related. We used measures developed under Objective 1 as dependent variables in the analyses conducted for Objective 2. Moreover, sampling decisions for some of the field work were made with both major objectives in mind.

Scope and Significance

Why Focus on QOL

Almost immediately after the enactment of Medicare and Medicaid, nursing homes became the focus of intermittent and intense attention because of quality and access problems. The current regulatory system for nursing-home care with its attention to standard setting, quality assessment, and enforcement, has, in part, evolved as a response to well publicized quality deficits. An Institute of Medicine Committee operating from 1983-1985, issued far-reaching recommendations on nursing-home quality (Institute of Medicine, 1986). Building on this and

other work taking place concurrently, the Nursing Home Reforms of 1987 took major steps to shape quality efforts for the next several decades, including: creating new quality standards for

QOL, resident rights and assessment; ushering in the development of the standardized Resident Assessment Instrument (RAI); developing a tiered approach to inspections; incorporating direct interviews with and observation of residents into quality assessments; establishing new intermediate sanctions short of removing the license of a substandard facility; and setting in motion the work to classify deficiencies by duration, scope, and severity.

Since 1987, nursing homes have, therefore, had explicit responsibility for meeting QOL standards. Also since then, the use of physical and chemical restraints in nursing homes has been curtailed with resultant improvement in QOL (Kane, Williams, Williams, & Kane, 1993). Nonetheless, regulatory attention has continued to focus on substandard care, which, of course, itself will affect QOL, rather than on QOL directly. In the decade since the 1987 reforms, quality indicators were forged using MDS data so that nursing homes could be profiled and compared according to care processes or outcomes—for example, incidence of new decubitus ulcers, or weight loss (Zimmerman et al., 1995). The development of measures and indicators for QOL had lagged behind. Surveyors express lack of confidence in citing facilities for QOL problems, and research showed that QOL citations were relatively seldom utilized (Harrington, Carrillo, Thollaug, & Summers, 1996).

The CMS contract with the University of Minnesota was meant to put a strong emphasis on QOL. It was let concurrently with other contracts that examined measures and indicators of quality of care for chronic and post-acute care in nursing homes (Abt Associates, 2001), examined MDS data accuracy, and studied ways to improve the survey process.

The importance of studying QOL goes beyond the CMS need to exercise its oversight and regulatory responsibility. The topic is also important because of mounting evidence that QOL is perceived as substandard in most nursing homes, even those that comply completely with quality

of care expectations. A new Institute of Medicine report released at the turn of the century concluded that although some progress had been made in improving overall quality of care in nursing homes, nursing homes are, nevertheless, dreaded institutions because of their toll on the QOL of their residents (Wunderlich & Kohler, 2001).

Significance of Environmental Studies

The relationship between the physical environment of the nursing home and the QOL of residents is a topic of longstanding interest. Powell Lawton pointed out years ago that environments need to offer both stimulation and support, and that the frailer the individual the more they need environmental supports to enhance functioning (Lawton & Nahemow, 1973). At the time CMS let its QOL contract, considerable attention had been given to environmental modifications in traditional nursing homes designed to create smaller living neighborhoods. These were thought to be associated with better QOL.

CMS also requested that special attention be given to studying the effects of private rooms on QOL. Over the years, the literature is replete with speculation and many strong opinions on the advantages and disadvantages of shared rooms in nursing homes. During the 1970's and 1980's, some conventional wisdom asserted that the shared room offered advantages in companionship and less isolation for nursing home residents. In the face of intermittent research on consumer preferences and outcomes related to shared or private-occupancy accommodations (Jenkins, 1997) (Kane, Baker, Salmon, & Veazie, 1998) (Lawton & Bader, 1970) (Teresi, Holmes, & Monaco, 1993), shared rooms gradually have had fewer defenders on their intrinsic merits. Evidence has mounted that residents prefer privacy (even if rooms are smaller and the tradeoff is less public space) and that residents who do socialize with other residents often

choose someone other than their roommate for this friendship. More recent considerations focused on costs, both capital costs for building new facilities with single rooms and operational costs. Some attention has also been given to the question of whether all populations benefit equally from single rooms, and whether some consumers (perhaps those with dementia) receive some benefit in terms of reduced agitation from a shared room. The merits of single versus shared rooms has somewhat been conflated with the effects of mingling residents with and without dementia or separating some people with dementia into dementia special care units; obviously any negative effects of co-mingling those with and without dementia are mitigated by single occupancy rooms, which provide everyone with some private space.

The 1986 Institute of Medicine report recommended that CMS (then HCFA)¹ conduct a study of the benefits of single versus shared rooms for residents with various characteristics to help inform a possible mandated ratio of single rooms to shared rooms in all new construction or major renovations (Institute of Medicine, 1986). That private room study was not initially commissioned, but the recommendation along with the development of alternative assisted living services that typically have private rooms or apartments, underscored the importance of examining the effects of single rooms on QOL in the current study.

Expected Users of QOL Measures and Indicators

The resultant measures, protocols and research findings were meant to be used by multiple groups, including: survey and certification agencies; nursing homes themselves; and consumers and their agents. Possible uses for each potential group of users are discussed briefly below.

¹ Henceforth, we will use CMS to designate the agency regardless of date reference.

Survey and certification personnel. Two general and not mutually exclusive considerations for Survey and Certification agencies undergirded the study: 1) the possibility of expanding and modifying current survey activities to better measure and address the statutory responsibility for QOL; and 2) the possibility of changing fundamental regulatory approaches regarding QOL. The Survey and Certification process has been extensively refined over the last decade, especially capitalizing on the investment in a uniform Resident Assessment Instrument (RAI), Minimum Data Set (MDS) and in Quality Indicators (QIs). However, attention to determining the adequacy of QOL has not kept pace with the developments in other spheres. The work reported here is meant to yield tools that surveyors could use to assess the QOL of individual residents and in facilities or to explore QOL in greater depth when a preliminary review suggests QOL may be lacking. It also could suggest strategies for sampling residents, including risk factors for a lower QOL and sample size needed to estimate QOL in a facility.

Surveyors currently rely heavily on data from the MDS (i.e. the resident assessment) and on the On-Line Survey and Certification Review (OSCAR), the computerized database that describes the results of the survey process and also records certain “census” data that facilities are required to submit to CMS in conjunction with the survey process. It is conceivable that new resident-specific data elements could be added to the MDS that explicitly relate to QOL, and that OSCAR could be based on data reported by facilities that are more relevant to QOL. The study was meant to yield recommendations in that regard and indeed has been used to inform the draft version of the MDS 3.0, being tested in the fall of 2003.

Finally, this line of study could raise issues about the adequacy of regulations themselves in relation to QOL. This is particularly likely in the area of physical environments.

Providers. QOL is an outcome best viewed on a continuum. Although from a regulatory perspective surveyors need to determine whether a facility has met a threshold of compliance, these determinations will have greatest relevance for a small subset of poor performing facilities. It is, therefore, likely that such facilities will already have been identified as substandard on quality of care.

Providers have an interest in identifying tools that can be used to characterize QOL in a facility so as to: a) compare their QOL to that of other facilities in the country and state; b) compare QOL of residents by resident characteristics or by distinct areas in the facility; and c) chart progress in improvement of QOL scores over time. Such tools could be used as the basis for a facility's Continuous Quality Improvement (CQI) efforts. To be useful in that regard, the tools should also tap positive aspects of QOL, not just the absence of negative results that would lead to regulatory citations. Also to be useful, tools must be easily understood and applied by facility staff. A test of feasibility of transferring tools to facility staff was built into this study.

Consumers, consumer advocates, and purchasers. The products of this study were meant to be useful for consumers and their agents. It was hoped that such tools could inform the presentation of comparative information about nursing homes to aid potential residents and their families in selecting a nursing home and purchasers of care in selecting programs to be covered in their plans; website technology makes such efforts particularly plausible. Also, groups such as long-term care ombudsmen and community-based case managers could potentially use the tools to generate their own information.

Other group care settings. This study was directed explicitly at nursing homes. Other care settings have evolved, however, besides nursing homes and the residents' own home. QOL is also an issue in residential care facilities, assisted living facilities, and adult foster care, for

example. Potentially, the measures and indicators developed in this study could be adapted to such rapidly proliferating settings. Tools are needed that permit comparisons of QOL for residents in nursing homes and in other licensed care settings.

Assumptions

The following assumptions and decisions helped put boundaries around this ambitious project:

Emphasis on Psychological and Social Components of QOL

To avoid duplicating other efforts underway at CMS, the scope of this study emphasized social and psychological aspects of QOL rather than, for example, including health status and functional abilities as domains of QOL. Only two of the domains of QOL we ultimately selected overlap a little with MDS-derived measures. For example, the comfort domain may overlap with pain assessment on the MDS, but we emphasized the subjective experience of a wide variety of physical discomforts, not just physical pain; also we argue that physical comfort is an area that is particularly subjective and, therefore, needs to be measured through direct interview questions rather than staff ratings. We also developed a domain, called functional competence, which is related to abilities to perform ADL functions. Again our functional competence domain taps a different dimension, because our emphasis was on the extent to which residents believe they are as independent as they can be and want to be. Chapter 3 describes our domain definitions and how we arrived at them.

Inclusions and Exclusions of Residents

The scope of the work was explicitly defined to include residents with a range of cognitive capabilities, including those with advanced Alzheimer's disease, as long as they could reply to questions. The study also included both long-stay and recently admitted residents. In this study, however, we did not make an effort to develop an individual-level measure of QOL to be

applied to residents close to death that included quality of dying. Samples of residents within days of death, such as some hospice residents, would be too small for measurement development without an explicit effort to over-sample the dying and this seemed more suited to a subsequent study.

The scope of the study was largely limited to people over age 65. Although substantial numbers of younger adults are also served in nursing homes, their QOL may be defined somewhat differently than the QOL of the largely very old group of seniors in nursing homes. Moreover, the proportion of younger persons in any nursing home tends to be small. Thus, for this developmental study, we concentrated on the older resident.

Exclusions of Facilities

In keeping with our attention to seniors, we excluded from the study facilities dedicated to serving residents with mental retardation and developmental disabilities. We also excluded Veterans Administration Nursing Home Care Units and State Veteran's Homes and any facilities that accepted neither Medicaid nor Medicare. (This exclusion permitted us to utilize the databases in place under Medicare and Medicaid without missing data). We also excluded swing beds and any hospital-owned nursing homes where the nursing home was not clearly distinct from the hospital; many of the questions in this study concern physical environments and, within the resources available, we wanted to standardize those environments somewhat by excluding those in hospitals. To summarize, our focus was on nursing homes that accept either Medicare or Medicaid, excluding federal facilities, MR-DD facilities, and swing beds in hospitals.

Residents as Gold Standard

This study took as a departure point that the reports of residents on the quality of their own lives should be sought and used whenever possible. QOL is, at least in large part, a subjective phenomenon, and no better substitute could be identified than asking the residents about their lives. Moreover, asking residents to model the very behavior needed in nursing homes to better individualize care; the very act of systematically talking to residents about their views of their own well-being rather than rating these same outcomes from a professional viewpoint can help bring about the desired results: better QOL.

Need to Supplement Resident Self Report

On the other hand, the reports of residents of their QOL could be rendered inaccurate by a number of factors. Residents might understate their QOL because of intimidation, reluctance to criticize a service on which they are dependent, courtesy and a wish to appear grateful, lack of knowledge about what could be expected in terms of a better QOL, or accommodation to poorer QOL. For that reason, we wished to develop QOL measures with some other sources of data for comparison. More importantly, we were aware that substantial numbers of residents would be unable to give any verbal self-report at all, and their QOL was also a concern for the study.

Multiple Sources of Information

In this study, we used four sources of information to measure QOL at the individual level: resident self-report, report of a knowledgeable staff member about a particular resident's QOL, report of a family member about his/her own relative's QOL, and systematic observation of the resident's emotions. We were interested in learning the extent to which the 3 other sources of resident-specific data (family report, staff report, and observation of residents) paralleled the resident self-report in its results. Although we intended to push hard to include self-reports from

residents with cognitive impairment, we also needed to develop a way of assessing QOL for an individual resident when that resident could not give his or her own report.

Dimensionality of QOL

We conceptualized QOL as entailing multiple dimensions, or domains. As already stated, by design, the study emphasized psychological and social domains of QOL rather than including health status, functional abilities, emotional health, and cognitive abilities as aspects of QOL. But within the aspects of QOL that we covered, the task included specifying relevant QOL domains.

Measures and Indicators Defined

For the purpose of this study, we defined a *measure* as any QOL outcome experienced by an individual resident. These could be reported by the residents themselves, by staff, or by family, or, to some extent observed, but such measures, regardless of data source, were meant to capture any specific resident's QOL outcomes. For this study, we initially identified and attempted to develop measures for 11 domains of QOL at the individual level. We also developed some general or summary measures of individual QOL for each individual.

We use the term *facility-level* QOL measures to refer to facility-wide averages on the individual QOL measures. We also designed the study so as to be able to generate aggregate scores for subsets of the nursing-home residents based on the geographic unit where the resident resided (i.e., the nursing unit) or on other resident characteristics (e.g., all residents with dementia at a specified threshold). If a measure of QOL is incapable of distinguishing among nursing homes, it is of little utility for regulatory purposes.

In contrast to the measures, an indicator was defined as a facility-level characteristic or attribute that could be studied for its *association with* resident-level QOL. To be useful, such indicators should predict QOL for the majority of a facility's residents or for a majority of some

subset of residents of interest even though individual residents can have results that run counter to the expected direction of the indicators. Indicators may include attributes of staffing, programming, or physical environments. It is possible that facility-level QOL measures collected at an earlier time also will serve as indicators for QOL at a subsequent time period.

We used the term *off-site indicator* to refer to data that could be assembled from extant data sets without a requirement that a facility be visited. Such indicator data currently could be derived from the Minimum Data Set (MDS) data that facilities submit to their states and CMS, and from data on the survey process and its results now found in the On-Line Survey and Certification Assessment Review (OSCAR). Some states aggregate other data such as complaint data in ways that might potentially be used as indicators of QOL. We are also collecting programmatic information on site that may serve as QOL indicators and lead to suggestions of additional information that could be provided by nursing home staff.

Organization of the Report

This report brings together in one place all the major facets of work done under this 5-year project. In some instances, more detailed material is available in reports to CMS and from the authors. Earlier reports to CMS or published articles are cited when applicable.

Chapter 2 outlines in broad terms our research questions and methods of data collection and data analysis. Because the report touches on so many different kinds of analysis using such a wide array of data sets, for greater clarity we present the more detailed methodology content in the same chapters where results are presented.

Chapter 3 presents the results of our 2-stage work in creating measures of QOL. It discusses the development of the domain structure and the instruments. The two major sections of Chapter 2 present the results of Wave 1 and Wave 2 of data collection. Wave 1 analyses are particularly useful to show the proportions of residents with cognitive impairment who could complete QOL

interviews and from whom we could generate scales. In Wave 2, we confirmed slightly revised measures using a larger sample of facilities. This chapter presents the scale properties, validation data, and factor structure for the measures.

In Wave 1, we identified a line staff caregiver to complete QOL questions as proxy respondent for each participating resident, and we identified a family member to complete the QOL questionnaires as a proxy for most residents. Chapter 4 presents the analyses that show the extent to which families or staff were accurate proxies for resident responses. We also used a protocol to assess resident emotions (interest, happiness, sadness, anger, and anxiety) based on the Apparent Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996). We present only limited analyses on this component, which we concluded was impractical for widespread application.

We developed a measure of personality suitable for administration to nursing home residents, which we administered in Wave 2. Chapter 5 describes the measure development and how personality, measured with this tool, was related to QOL.

The next step was to determine whether and how QOL measures distinguished among facilities. In Chapter 6, we present average QOL data, by facility, for both waves. We also describe how resident and facility characteristics affect QOL scores.

Chapter 7 describes approaches to developing short screeners on QOL using the larger battery of items.

Chapter 8 reports our development of a protocol for facility-level observations of resident and staff interactions, which were made during systematic walks through the facility, and stationary observations of meals and activities. These observational tools were meant to complement the QOL measures, and permit inclusion of units largely housing residents who

were unable to participate in interviews. The chapter reports the relationship between the observations and facility-level QOL scores.

Chapter 9 describes potential indicators of QOL collected in visits to the facilities at Wave 1, and, more compactly, in an administrator-completed questionnaire in Wave 2. The chapter discussed some of the challenges of collecting these data and describes their correlation with QOL.

Chapter 10 describes how specific extant data derived from the MDS and the On-Line Survey and Certification Assessment Review (OSCAR) are related to QOL.

Chapter 11 presents the results of a field test to determine the extent to which nursing home staff and state surveyors could apply the resident interview measures and the observations and achieve the same results as research interviewers.

Chapter 12 summarizes results of the environmental studies.

Chapter 13 briefly discusses the implications of all the work to date and describes desirable next steps for research with these data and follow-on studies. .

Volume 2 assembles all the questionnaires and protocols fielded in this study.

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